

VHA Multiple Sclerosis Surveillance Registry and its similarities to other contemporary multiple sclerosis cohorts

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Abstract—The Veterans Health Administration (VHA) has provided important contributions to our understanding of multiple sclerosis (MS); however, the characteristics of the modern VHA MS population have not been adequately characterized. Our objectives were to compare and contrast characteristics of the VHA MS population with other contemporary MS cohorts. A cross-sectional, mail-based survey of a stratified, random sample of 3,905 VHA users with MS was conducted. Detailed demographic and clinical data were collected as well as patient-reported outcomes assessing disability and quality of life. A total of 1,379 Veterans were enrolled into the MS Surveillance Registry (MSSR). Respondents did not differ from nonrespondents with regard to demographics or region. When compared to several other contemporary MS cohorts, some demographic differences were noted; however, the age of MS onset and diagnosis, subtype distribution, and most prevalent symptoms were very similar across MS cohorts. The MSSR appears to be representative of the general MS population. Combining the extensive VHA health services encounter data with the MSSR provides a rich and unique cohort for study.

Key words: epidemiology, MS, MS characteristics, MS cohort, MS population, MSSR, multiple sclerosis, surveillance registry, Veterans, Veterans Health Administration.

INTRODUCTION

The Veterans Health Administration (VHA) is home to one of the United States' largest integrated healthcare systems, providing comprehensive healthcare to more than 8.3 million Veterans annually [1–2]. Since 1998, more than 30,000 VHA users have been diagnosed with multiple sclerosis (MS), of whom about 17,000 are seen in the VHA annually. Studies of MS within the VHA have contributed to our understanding of MS since the

Abbreviations: DMT = disease-modifying therapy, MS = multiple sclerosis, MSIS-29 = MS Impact Scale, MSSR = MS Surveillance Registry, NARCOMS = North American Research Consortium on MS, NYMSC = New York MS Consortium, PDDS = Patient Determined Disease Steps, SLIFKA = Sonya Slifka Longitudinal MS Study, VA = Department of Veterans Affairs, VHA = Veterans Health Administration.

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1950s [3–5]. Recently, we reported an increase in MS incidence among Gulf War era Veterans compared with military cohorts from prior conflicts [6]. Others have also reported an increase in the incidence and prevalence of MS, suggesting a changing demographic (more women and an older population) [7–10]. It is not known, however, whether the clinical profile of MS has changed as well.

At present there is no gold standard MS cohort/registry in the United States nor has there been a comparison of the MS databases that do exist. To further our understanding of risk factors for the development and progression of MS as well as to conduct comparative effectiveness studies, we need a large, longitudinal, and diverse cohort of MS patients. The VHA MS population may provide one such cohort as the VHA catchment area covers all 50 states and Puerto Rico, the population is ethnically diverse, and detailed healthcare utilization and pharmacy costs are maintained for all its enrollees.

Despite the many contributions from Veteran MS cohorts to our understanding of the epidemiology of MS, there is the perception that the Veteran MS population is very different from the at-large, civilian MS population [11–12]. Our recent experience suggests that MS within the VHA is more similar to the general MS population than has been previously appreciated. Thus, the aims of this study were twofold. First, create the VHA MS Surveillance Registry (MSSR) and provide a detailed description of the epidemiologic and clinical composition of the modern VHA MS population. Second, provide an updated description of the epidemiologic and clinical characteristics of MS in the United States by contrasting the characteristics of the MSSR with other published MS cohorts [13–15].

METHODS

Multiple Sclerosis Surveillance Registry Cohort

A total of 16,808 MS cases were identified by a statistical algorithm [16]. Briefly, a Veteran was classified with MS if they (1) had a service-connected disability for MS, (2) had ever been prescribed an MS-specific disease-modifying therapy (DMT), or (3) had two or more encounters with MS listed as the primary diagnosis in each year since entering the VHA MS cohort. Sensitivity and specificity, compared with chart review, was better than 0.90 and 0.93, respectively.

From this cohort, 7,436 cases were excluded (2,986 were deceased, 3,082 did not have a mailing address, and 1,368 had less than 1 yr of data). Of the remaining 9,372 cases, all female Veterans ($n = 1,548$) and a sample of 2,357 male Veterans stratified proportionally by geographic region were selected. Females were over-sampled to ensure large enough numbers for adequate comparisons by sex. The resulting survey sample ($n = 3,905$) represented 42 percent of the sampling pool.

This study was approved by the Institutional Review Board of the University of Maryland, Baltimore, and the Department of Veterans Affairs (VA) Maryland Health Care System's Research and Development Committee.

Survey Methods

A mail-based survey following the recommendations of Dillman [17] and Edwards et al. [18] was used to solicit participation in the MSSR and collect baseline data (**Table 1**).

Table 1.

Survey domains and content.

Domain	Data Elements/Questionnaire Used
Demographics	Age, sex, race, ethnicity, marital status, education, income, employment, living situation, insurance.
Clinical History	Date of onset and diagnosis, MS subtype (RRMS, SPMS, PPMS, PRMS), recent relapse history.
DMT	Chronological history of DMT use, reasons for stopping/switching, new DMT change.
Disability	MS-related disability: PDDS [19].
ADLs	ADLs requiring assistance [20].
MS Symptoms	MSSC [21].
Comorbidity	Elixhauser comorbid conditions from extant utilization data [22].
MS QoL	MSIS-29 [23].
Generic QoL	SF-12 [24].

ADLs = activities of daily living, DMT = disease-modifying therapy, MS = multiple sclerosis, MSIS-29 = MS Impact Scale, MSSC = MS Symptoms Checklist, PDDS = Patient Determined Disease Steps, PPMS = primary-progressive MS, PRMS = progressive-relapsing MS, QoL = quality of life, RRMS = relapsing-remitting MS, SF-12 = 12-Item Short Form, SPMS = secondary-progressive MS.

The initial mailing consisted of a cover letter describing the project; a consent form; a Health Insurance Portability and Accountability Act form; the survey; and a self-addressed, postage-paid return envelope. Approximately 6 weeks after the initial mailing, another packet was mailed to all nonresponders. A third packet was again mailed to all nonrespondents 6 weeks after the second mailing. The survey period was closed 6 weeks after the third mailing in the fourth quarter of 2008.

Multiple Sclerosis Cohorts

The New York MS Consortium (NYMSC) [13], the Sonya Slifka Longitudinal MS Study (SLIFKA) [14], and the North American Research Consortium on MS (NARCOMS) Spring 2012 survey provided comparisons for the MSSR. The NYMSC, SLIFKA, and NARCOMS are the largest published MS cohorts in the United States and have been reasonably well characterized in the literature.

Statistical Methods

Response rate was computed according to the American Association for Public Opinion Research [25]. Simple percent agreement was used to assess the reliability of patient-reported MS subtype, DMT use, and consistency across the three MS Impact Scale (MSIS-29) items that were repeated. For comparisons of responders and nonresponders, we computed the percent difference and conservatively defined 5 percent as a meaningful difference, as all comparisons were statistically significant due to the large sample size.

Statistical comparisons between cohorts were not done because the primary interest was the degree to which these cohorts were similar or different as opposed to whether they were derived from different populations. Thus, only descriptive comparisons are reported. Data for the NYMSC and SLIFKA cohorts were abstracted from tables and charts presented in their seminal publications. NARCOMS provided summary data from their 2012 survey reported separately by Veteran status (self-reported). Study data are displayed in tabular form and presented as frequency and percent for categorical data and as means and standard deviations for continuous variables.

RESULTS

Response Rate

Of the 3,905 Veterans surveyed, 1,379 gave consent to participate in the MSSR and completed the survey, yielding a response rate of 36 percent. To assess for pos-

sible respondent bias, we compared key demographic variables and use of DMT (from VHA data sources) between responders (MSSR participants) and nonresponders (**Table 2**).

Only marital status and DMT utilization differed ($\geq 5\%$ difference). The proportion of MSSR participants who were married was 8.2 percent greater than among nonparticipants, and the rate of DMT use was 6.2 percent greater in MSSR participants compared to nonparticipants.

Data Validations

The reliability of patient-reported MS subtype was assessed by comparing survey responses to chart review subtype obtained from previous validation efforts [16]. Based on 41 matched pairs, there was 100 percent agreement when subtype was dichotomized as relapsing versus progressive (69% agreement when based on all four subtypes). The lower agreement across the four subtypes was due exclusively to discrepancies between relapsing-remitting and secondary-progressive MS.

Comparisons between self-reported DMT utilization and prescription-level data were performed for all DMTs and separately for the first through the third DMT sequentially used. When the order of DMT use was considered, there was 85 percent agreement. Agreement increased to 90 percent when comparing DMT use overall, without regard for order of use.

Agreement between the three MSIS-29 items that were repeated was 97, 97, and 96 percent.

Demographic Characteristics

The demographic characteristics of the MS cohorts are provided in **Table 3**. Not all of the comparison cohorts provided detailed demographic data or data had to be extrapolated from tables or figures, limiting comparisons for some characteristics. Overall, the demographic composition was similar across cohorts with the exception of the sex distribution. In the MSSR, by design, the female-to-male ratio was 1:1, whereas the ratio was 1.8:1 to 5.8:1 in the other cohorts. The mean age of participants differed across all four cohorts and paralleled the year in which the data were published. The NYMSC had the youngest mean age and was assembled over 13 years ago, whereas NARCOMS had the highest mean age and was compiled in the spring of 2012.

All four cohorts were composed of predominantly Caucasians, with non-Veteran NARCOMS and the NYMSC almost exclusively Caucasian (97% and 93%, respectively). The MSSR was the most ethnically diverse

Table 2.

Comparisons of MSSR participants versus nonparticipants.

Variable	Participants [*]	Nonparticipants [†]	Difference
<i>N</i>	1,379	2,356	—
Age, yr (mean ± SD)	54.7 ± 9.7	53.1 ± 10.4	−1.6
Sex (% male)	52.6	53.7	−1.1
Marital Status (%)			
Never Married	14.7	22.2	−7.5
Married	61.4	53.2	+8.2
Race (%)			
Caucasian	82.2	78.1	+4.1
African American	14.8	18.5	−3.7
Income (in \$1,000)	32.7 ± 57.3	30.7 ± 49.2	+2.0
Medicare Enrollee (%) (1999–2006)	49.1	48.2	−0.9
Proportion with Service- Connected Disability for MS (%)	54.7	58.1	−3.4
DMT (% ever used DMT)	78.1	72.0	+6.2
Region (%)			
Northeast	17.8	17.7	+0.1
Southeast	21.3	21.3	0
Midwest	16.6	15.9	+0.7
Midsouth	11.8	15.9	−4.1
Northwest	19.9	15.8	+4.1
Southwest	12.6	13.4	−0.8

^{*}Participants were those Veterans who returned completed survey and consented to be in MSSR.[†]Nonparticipants includes Veterans who did not respond at all and those that declined participation.

DMT = disease-modifying therapy, MS = multiple sclerosis, MSSR = MS Surveillance Registry, SD = standard deviation.

of the cohorts, with 13 percent African-American. Marital status was similarly distributed across the cohorts with 60 to 66 percent being married or living with a domestic partner. Employment status was reported differently for SLIFKA and the NYMSC (**Table 3**), which may account, in part, for some of the observed differences. Overall, the Veteran cohorts (MSSR and Veteran NARCOMS) reported the lowest proportion employed and highest proportion retired. However, it should be noted that 55 percent of the MSSR (and likely a similar proportion among Veteran-NARCOMS participants) had a service-connected disability for MS that provided a financial benefit in addition to a medical benefit.

Level of education was comparable between the MSSR and the SLIFKA cohorts but a little lower than the

NARCOMS cohorts. Family income appeared roughly comparable across cohorts, although 20 percent of the MSSR declined to report their income. Types of insurance were reported differently but overall varied across cohorts in a predictable manner. Patients enrolled in NARCOMS and NYMSC were predominantly privately insured, whereas nearly a third of patients in the MSSR had Medicare coverage in addition to VHA coverage. Insurance data in the SLIFKA cohort was reported as the proportion with Social Security disability and was very similar to Medicare coverage in the MSSR.

Clinical Characteristics

Table 4 provides a summary of the clinical characteristics of the MS cohorts, where available. Age at symptom

Table 3.

Comparison of demographic characteristics between multiple sclerosis (MS) cohorts (data presented as frequency [%] except where otherwise indicated).

Variable	MSSR	NARCOMS Veterans*	NARCOMS†	SLIFKA‡	NYMSC§
<i>N</i>	1,379	1,434	6,854	2,156	3,019
Reference Year	2009	2012	2012	2006	1999
Sex					
Male	725 (53)	798 (56)	1,002 (15)	470 (23)	797 (26)
Female	654 (47)	636 (44)	5,851 (85)	1,686 (77)	2,222 (74)
Male:Female Ratio	1.1:1.0	1.3:1.0	1.0:5.8	1.0:3.6	1.0:2.8
Age, yr (mean ± SD)	54.7 ± 9.7	61 ± 10.0	56 ± 10.1	50.7 ± 10.6	45.2 ± 11.2
Race					
Caucasian	1,133 (82)	1,308 (91)	6,655 (97)	1,871 (87)	2,789 (93)
African American	183 (13)	7 (~1)	34 (~1)	104 (5)	187 (6)
Other	63 (4)	119 (8)	165 (2)	165 (8)	33 (1)
Marital Status					
Married	816 (59)	919 (64)	3,982 (58)	1,426 (66)	—
Separated/Divorced	378 (28)	367 (26)	1,782 (26)	376 (18)	—
Never Married	131 (10)	120 (8)	932 (14)	254 (10)	—
Widowed	42 (3)	28 (2)	158 (2)	99 (5)	—
Employment Status					
Employed (FT/PT)	255 (19)	359 (25)	2,563 (37)	1,040 (44)¶	1,459 (48)**
Volunteer	50 (4)	161 (13)	1,782 (26)	1,114 (56)	—
Not Working	395 (29)	264 (18)	1,487 (22)	—	668 (22)
Retired	660 (48)	631 (44)	2,029 (30)	—	—
Education					
<High School	43 (3)	17 (~1)	55 (~1)	75 (4)	43 (3)
High School/GED	332 (24)	384 (27)	1,734 (25)	486 (23)	332 (24)
Some College	484 (35)	327 (23)	1,391 (20)	682 (33)	484 (35)
College Degree	329 (24)	377 (26)	2,070 (30)	436 (24)	329 (24)
Graduate Degree	191 (14)	328 (23)	1,604 (23)	337 (16)	191 (14)
Family Income (\$)					
<15,000	165 (12)	135 (10)	610 (9)	126 (7)††	—
15,000–30,000	269 (20)	250 (17)	946 (14)	191 (10)	—
30,000–50,000	311 (23)	354 (25)	1,556 (23)	751 (38)	—
≥50,000	352 (25)	600 (42)	2,070 (47)	981 (45)	—
Declined	282 (20)	95 (7)	548 (8)	—	—
Insurance					
Medicare	444 (32)	205 (14)	1,234 (18)	685 (37)§§	612 (21)¶¶
Commercial Private	272 (20)	743 (52)	4,900 (72)	247 (12)	2,348 (79)
CHAMPUS/TriCare	214 (16)	376 (26)	123 (2)	—	—
Other	33 (2)	85 (6)	480 (7)	—	—

*Spring 2012 North American Research Consortium on MS (NARCOMS) data for participants self-reported as Veterans.

†Spring 2012 NARCOMS data for non-Veteran participants.

‡Sonya Slifka Longitudinal MS Study (SLIFKA) [14].

§New York MS Consortium (NYMSC) [13].

¶Employment status dichotomized as “in labor force” or “not in labor force.”

**Employment data extrapolated from Figure 6, Jacobs et al. [13].

††Income categories differed in SLIFKA: <10,000; 10,000–25,000; 25,000–50,000; and ≥50,000.

§§Insurance was reported as disability income from either Social Security or private sources.

¶¶Insurance data extrapolated from Figure 7, Jacobs et al. [13].

CHAMPUS = Civilian Health and Medical Program of the Uniformed Services, FT = full time, GED = General Educational Development, MSSR = MS Surveillance Registry, PT = part-time, SD = standard deviation.

Table 4.

Comparison of clinical characteristics between multiple sclerosis (MS) cohorts (data presented as frequency [%] except where otherwise indicated).

Variable	MSSR	NARCOMS Veterans*	NARCOMS†	SLIFKA‡	NYMSC§
<i>N</i>	1,379	1,434	6,854	2,156	3,019
Reference Year	2009	2012	2012	2006	1999
Age, yr (mean ± SD)					
Age at Onset	32.8 ± 10.2	31 ± 10.4	31 ± 9.9	—	32.7 ± 9.7
Age at Diagnosis	38.4 ± 9.9	39 ± 9.8	38 ± 9.7	—	37.0 ± 10.4
Disease Duration, yr (from diagnosis) (mean ± SD)	15.6 ± 9.7	21 ± 10.7	17 ± 9.1	13.0 ± 9.3	8.2 ± 7.8
MS Subtype					
Relapsing-Remitting (RR)	692 (51)	594 (41)	4,064 (59)	1,314 (58)	1,657 (55)
Secondary-Progressive (SP)	456 (34)	356 (25)	1,371 (20)	463 (25)	933 (31)
Primary-Progressive (PP)	177 (13)	185 (13)	507 (7)	243 (12)	283 (9)
Progressive-Relapsing (PR)	34 (2)	—	—	87 (5)	146 (5)
Relapsing (RR & SP)	1,148 (84)	950 (80)	5,435 (88)	1,777 (83)	2,590 (86)
Progressive (PP & PR)	211 (16)	235 (20)	692 (12)	330 (17)	429 (14)
MS Symptoms					
Fatigue	1,103 (80) [¶]	1,130 (80) ^{**}	5,058 (74) ^{**}	1,787 (83) ^{††}	—
Difficulty Walking	1,083 (78)	1,113 (78)	4,502 (66)	1,350 (67)	—
Bladder Problems	589 (43)	837 (59)	3,450 (50)	1,202 (60)	—
Pain	749 (54)	—	3,443 (51) ^{‡‡}	1,200 (54)	—
Stiffness/Spasms	720 (52)	796 (56)	3,093 (45)	1,306 (63)	—
Memory Problems	605 (44)	727 (51) ^{§§}	2,969 (44) ^{§§}	1,202 (55)	—
Depression/Mood Problems	496 (36)	518 (36)	2,277 (33)	820 (37)	—
Vision Problems	394 (29)	557 (39)	2,261 (33)	801 (37)	—
Swallowing Problems	200 (15)	—	—	442 (22)	—
Disability (PDDS)^{¶¶}					
None/Mild Symptoms	154 (11)	264 (18)	2,132 (31)	442 (18)	—
Mild Symptoms	118 (9)	92 (6)	528 (8)	573 (24)	—
Minor Problems Walking	186 (13)	175 (12)	809 (12)	233 (10)	—
Walk 25 ft w/o Cane	236 (17)	229 (16)	973 (14)	197 (9)	—
Cane to Walk 25 ft	216 (16)	174 (12)	754 (11)	308 (14)	—
Bilateral Support	127 (9)	184 (13)	761 (11)	123 (7)	—
Wheelchair/Scooter	293 (21)	294 (21)	850 (12)	270 (15)	—
Bedridden	32 (2)	23 (2)	548 (1)	7 (<1)	—

*Spring 2012 North American Research Consortium on MS (NARCOMS) data for participants self-reported as Veterans.

†Spring 2012 NARCOMS data for non-Veteran participants.

‡Sonya Slifka Longitudinal MS Study (SLIFKA) [14].

§New York MS Consortium (NYMSC) [13].

¶Symptoms assessed with MS Symptom Checklist and [21].

**Symptoms assessed by Performance Scales [26].

††Symptoms assessed using structured interview and MS Quality of Life Inventory [27].

‡‡Pain ratings taken from the 2002 survey [28] and not broken-out by Veteran status.

§§Closest approximation with Performance Scale was Cognitive Disability domain.

¶¶Patient Determined Disease Steps (PDDS) [19].

MSSR = MS Surveillance Registry, SD = standard deviation, w/o = without.

onset and age at diagnosis were nearly identical across the cohorts. Mean current age and disease duration from diagnosis varied across the cohorts, with the greatest age and disease duration found in NARCOMS, the most recently collected data. Age and disease duration were 21 and 17 yr for Veterans and non-Veterans, respectively, whereas the NYMSC had the youngest current age and shortest disease duration (8 yr) but the data were collected 13 yr ago. MS subtype was remarkably similar across the four cohorts and nearly identical when dichotomized as relapsing versus progressive.

Current MS-related symptoms for the SLIFKA cohort were collected via structured interview and MS Quality of Life Inventory [28], whereas the MSSR used the MS Symptom Checklist [21]. NARCOMS used the Performance Scales [26] to assess symptoms except for pain, which was assessed by a single pain question [27] validated against the Pain Effects Scale [29]. Only those symptoms for which a reasonable match could be ascertained across instruments are reported in **Table 4**. Fatigue, difficulty walking, bladder problems, and pain are among the most commonly reported symptoms and were distributed similarly across cohorts. The higher rates for stiffness/spasms, memory problems, vision problems, and swallowing problems in the SLIFKA cohort are due in part to the way the data were collected (i.e., structured interview vs patient report).

Disability was assessed using the Patient Determined Disease Steps (PDDS) [19] across cohorts except for the NYMSC, which did not report disability. Overall, patient-reported disability levels were similar across cohorts, although the Veteran groups (MSSR and Veteran NARCOMS) tended have a smaller proportion reporting “no or mild” disability and a slightly greater proportion that required ambulatory assistance than non-Veteran NARCOMS and SLIFKA.

DISCUSSION

This report provides a description of the methods used to create the VHA MSSR and provides comparisons of the demographic and clinical composition with several other large U.S. MS cohorts [13–15]. This is the first study to provide a detailed description of the contemporary VHA MS population and compare the epidemiologic characteristics across several large MS cohorts from the

United States. Overall, the demographic and clinical characteristics were similar across cohorts.

Our 36 percent response rate was lower than anticipated but similar to other recent mail-based surveys in MS patients [7]. The response rate for the SLIFKA cohort was 27.4 percent, was not reported for the NYMSC, and was not calculated in NARCOMS as participation was voluntary.

Within the VHA, there was a slightly higher proportion of participants compared to nonparticipants who were married (61% vs 53%) and had ever used a DMT (78% vs 72%). Thus, any respondent bias this may have created was likely small as well. When MS subtype was dichotomized as relapsing versus progressive, there was 100 percent agreement between patient report and chart review, and when patient-reported DMT usage was compared against pharmacy-claims data, there was 90 percent agreement. Additionally, agreement between the three items of the MSIS-29 that were repeated was high (>95%). Overall, these findings suggest that MS patients are a reliable source of clinical data as has been documented in other MS studies utilizing patient-reported surveys [15,29–31].

Even though the Veteran cohorts had the lowest proportion of females, the MSSR did enroll a sufficient number of females for meaningful analyses. In contrast, SLIFKA and the non-Veteran NARCOMS were predominantly female with ratios of 3.6 and 5.8 to 1, respectively. The NARCOMS ratio is higher than existing reports possibly due to sampling bias as participation in NARCOMS is voluntary and recruitment efforts did not include any sampling strategy. The ratio of females to males in the SLIFKA cohort is similar to that recently reported in the Gulf War era MS cohort [6] as well as in other MS populations [7–10], all of which supports an increase in the incidence of MS among females.

At first glance it appears that the SLIFKA and NYMSC cohorts are substantially younger than the MSSR and the NARCOMS cohorts, but this can be explained by population demographic changes [7–10]. The SLIFKA and NYMSC cohorts were published years earlier than the other cohorts with no recent updates to determine how much these cohorts may have aged. The mean age of the NARCOMS cohorts has increased by nearly 10 yr since its initial survey. In the 2002 NARCOMS survey [12], the mean age of the Veteran and non-Veteran groups was 53 ± 11 and 46 ± 10 , respectively, compared to 61 ± 10 and 56 ± 10 in the 2012 survey. The

older mean age of the MSSR and NARCOMS cohorts is in keeping with reports that the mean age of the MS population is increasing commensurate with the increasing prevalence of MS [7–10]. If current data were available for SLIFKA and NYMSC, it is likely that the difference in the mean age of these cohorts would be considerably less than observed here using their seminal publications.

In terms of race, all of the cohorts were predominantly Caucasian (82% or greater). The MSSR was the most ethnically diverse cohort, with 13 percent African-American and 4 percent other races. We recently reported that African Americans had a 20 percent higher risk for MS compared to Caucasians and that risk of MS in African Americans has increased from the World War II/Korean War conflict cohort, most notably in females [6]. These findings suggest that there has been a shift in the racial distribution among incident MS cases that warrants further study.

Marital status, education level, family income, and insurance coverage were similar. However, a smaller proportion of the MSSR cohort was employed. This may be due in part to the fact that 55 percent of the MSSR respondents had a service-connected disability for MS that provides a financial benefit in addition to healthcare coverage that can be as much as 100 percent of their base pay at the time they were discharged from Active Duty.

In contrast to the apparent changing demographics of MS, the clinical profile of MS appears remarkably stable. Age at symptom onset and at diagnosis, MS subtype, and current MS symptoms were highly consistent across all cohorts and are similar to the clinical profile of MS that has commonly been reported in the literature [32–33]. The one exception was for self-reported disability (PDDS), which was slightly greater among the Veteran groups (**Table 4**). Some of this difference is likely due to differences in the current age and disease durations between the cohorts noted previously as the Veteran groups tended to be a little older with longer disease duration.

Early reports from NARCOMS [11–12] characterized MS in the VHA as being composed of predominantly older males with progressive disease and severe disability. Veteran participants in that initial survey effort were drawn from the membership of the Paralyzed Veterans of America and the Eastern Paralyzed Veterans Association. One would expect such characterization, as these Veteran service organizations cater exclusively to Veterans with spinal cord injury and other physical disabilities.

The MSSR data presented here are a more accurate description of the current composition of MS among Veterans using the VHA and are much more similar to the general MS population than has been previously appreciated.

CONCLUSIONS

The present study shows that there is no gold standard data source from which one can definitively characterize the epidemiology of MS in the United States. Each of the reviewed cohorts has strengths and weaknesses, and investigators should review the data collection methods and sampling strategies of each cohort carefully with respect to their research question(s) when deciding which cohort(s) to use.

While some demographic differences were observed between cohorts, the clinical composition of the MSSR was very similar to the other MS cohorts. The observed differences were generally small, and the more germane clinical characteristics showed the greatest similarity across the reviewed cohorts. These findings suggest that the MSSR is generally representative of the larger MS population in the United States. The detailed healthcare utilization and cost data maintained by the VHA combined with data from the MSSR provides a unique and demographically diverse MS cohort for future study.

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Participant Follow-Up: Individual participants were not contacted about the completion of the study or the impending publication of this report. The logistics and costs of doing so were prohibitive. A brief description of the study and a link to *JRRD*'s Web site will be posted on the VHA MS Center of Excellence Web site so that all Veterans with MS can access the article.

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